

**Joint MPH Program**

**University of Gondar and Addis Continental Institute of Public Health**

**Assessment of Disability Status of New leprosy patient diagnosed between  
2000EFY to 2002EFY from record in Bisidimo Hospital, East Harage**

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## **ABBREVIATION**

AOR	Adjusted Odd Ratio
BCG	Bacillus Calamite Guerin
CDR	Case Detection Rate
CI	Confidence Interval
COR	Crude Odd Ratio
EFY	Ethiopian Fiscal Year
EPI INFO	Epidemiology Information
G2D	Grade 2 Disability
ICF	International Classification of Functioning, Disability and Health
MB	Multi- Bacillary
MDT	Multi -Drug Therapy
MOH	Ministry Of Health
PB	Pauci-Bacillary
POD	Prevention Of Disability
POWD	Prevention Of Worsening of Disabilities
TLCP	TB and Leprosy Prevention and Control Program
SPSS	Statistical Package for Social Science
WHO	World Health Organization

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## ABSTRACT

**Back ground:** While the National strategy on leprosy to date has focused on disease elimination, disability is the main concern of people affected by leprosy. There remain important challenges to fighting and controlling disability in new leprosy cases of Bisidimo Hospital and there continues to be a number of people with leprosy related disability who are in need of disability prevention services and rehabilitation. Absence of reliable data and lack of continuous research have added to the problem.

**Objective** of this study was to assess the disability status of new leprosy patient diagnosed between 2000EFY to 2002EFY from record in Bisidimo Hospital, East Harage.

**Methods:** Both quantitative and qualitative methods were used. For quantitative method individual registered cases of leprosy from records within the last three years period (2000-2002 EFY) were taken. Data were collected on their disability status, socio demographic and clinical factors using a leprosy record. Bivariate and multivariate analysis was employed to assess the associations between the independent and outcome variables. The study was supplemented qualitative part, in-depth interviews conducted to understand the possible factors contributing to grade two disabilities.

**Result:** Leprosy induced disabilities are very common in the study population 18.3 % of new patients presented with grade 2 disability. The bivariate and multivariate analysis revealed that age group, residence of patient and the presence of leprosy reaction were significantly associated with grade II disability among leprosy cases. The qualitative study revealed finding, almost all the disabled patients have lower knowledge and are poor.

**Conclusion and Recommendation:** from this study, the proportion of grade II disability was 18.3%, relatively higher than the national target of 5%. None of cases understand the importance of daily self care so that damage is not minimized. Such magnitude of grade II disability highlights the need for continued surveillance for early case detection and awareness raising activities on leprosy needed. So that cases of leprosy can be detected before people suffer the long-term consequences of disabilities. More easily accessible Prevention of disabilities services must be set up such services can give health education, advocate for these disabled in leprosy and improve their social and economic status of the poorer leprosy disabled people.





## 1. INTRODUCTION

Leprosy is one of the leading causes of physical disabilities which contribute to intense social stigma resulting in discrimination of patients and their families in many societies. Annually, around 12 000 – 14 000 new cases with grade-2 disabilities are detected globally. Amongst major endemic countries, the proportion of new cases presenting with WHO disability grade 2 was reported in 2010 to range from 1.45% to 22.8% [1, 9]. Early detection of leprosy patients and timely treatment with them in the World Health Organization recommended multi- drug therapy is key element of the strategy to halt the transmission of the disease and to bring about cure without disabilities. In dealing with these consequences of leprosy has not nearly been as successful as the progress in the antibacterial treatment of the disease. There continues to be a number of people with leprosy related disability who are in need of disability prevention services. It is essential that case-finding efforts are maintained if elimination is to be sustained. Where the control program was performing consistently well, the new case detection rate and the new cases with grade-2 disability rate are seen to be declining in parallel [1,3,9,28,29].

To reduce the proportion of grade 2 disability among new leprosy cases to less than **5%** by identifying new cases as early as possible is strategies of effective leprosy control program. According to Ethiopian Ministry of Health routine surveillance data the national proportion of Grade II disability for the last three years in EFY 2000, 2001 & 2002 are 9%, 7% and 9% respectively. In the same way number of new cases detected for the year of 2008 and 2009 is 4170 and 4417 respectively. In East Harage's Bisidimo Hospital new leprosy cases detected for the last four years in EFY 1999, 2000, 2001 and 2002 are 522,528,556,428 cases respectively. This shows still high burden of leprosy cases exists in Bisidemo Hospital. Significant proportion of leprosy patients coming to health facilities show disability at diagnosis and many will be at risk of developing disability after diagnosis. New nerve damage is often clinically silent in early stages but is not routinely checked for in many integrated leprosy control program. Many Studies revealed that the longer the delay between the appearance of the first symptoms of leprosy and the start of treatment, the more likely it is for nerve damage to occur [3,6, 7, 8, 27, 28].

While the National strategy on leprosy to date has focused on disease elimination, disability and stigma are the main concern of people affected by leprosy. Effective chemotherapeutic treatment

are available that have reduced the national disease burden dramatically, but there remain important challenges to fighting and controlling disability in new cases of Bisidimo Hospital and there continues to be a number of people with leprosy related disability who are in need of disability prevention services and rehabilitation. Absence of reliable data and lack of continuous research have added to the problem. Programs and services dealing with leprosy will continue to need input from research to inform policy and management [6, 9, 10, 28, 30].

In this specific study area no previous study has investigated on the issues of disabilities in leprosy. However, detail understanding of the status of disability in leprosy is essential to understanding of risk factors for effective prevention of disability. Despite the fact that disability plays such a major role in leprosy, very little research has been done on this issue. Techniques for Prevention of disability have been implemented within Bisidimo Hospital. However, a number of major operational problems remain to be overcome for effective wide-spread application must be realized. Issues regarding assessing patients at the time of diagnosis and on, validity and quality of data (whether grade 0 is reported or assumed, grading criteria, nerve function assessment and practical training needs) and interpretation of indicators in terms of individual impairment status need to be investigated. In most health facility, reliable epidemiological data on leprosy are difficult to collect for many reasons. However, Bisidimo Hospital, where the leprosy program is well organized and where medical records of leprosy patients are somewhat well documented. The reporting system was initiated under the authority of Oromiya regional Health Bureau. Reliable data on leprosy over the past three years in Bisidimo Hospital are thus available.

The enhanced global strategy for 2011–2015 emphasizes reduction of the number of cases with grade-2 disabilities. By 2015 an anticipated 35% reduction in grade-2 disability rate and this is expected to be attained at the global level. To set similar targets for this indicator taking into account the current trends of new case detection and the grade-2 disabilities rate should be investigated [1, 9, 11, 29]. The aim of this study was to assess the disability status of new leprosy cases among recorded cases of Bisidimo Hospital.

## 2. LITERATURE REVIEW

Disability is a broad term covering any impairment, activity limitation or participation restriction affecting a person[9,26,].While the impact of prevention of disability (POD) could therefore be assessed in terms of impairments, activity and participation, the main focus of interventions has been on preventing impairments, i.e., the physical level. POD may therefore be defined as ‘a concept comprising all activities at individual, community and program level aimed at preventing impairments, activity limitations and participation restrictions’. POD can be achieved by prevention of impairments and disabilities (POID) and prevention of worsening of disabilities (POWD), but often these do not accompany the services offered towards 'medical cure' at the grass root level. It is widely acknowledged that personal attitudes and circumstances, combined with environmental factors can either precipitate, or help prevent disability in leprosy.[,9,26,27].

**How is disability assessed and recorded in leprosy?** Every new case of leprosy must be assigned a Disability Grade, which shows the condition of the patient at diagnosis. The grade is 0, 1 or 2. Each eye, each hand and each foot is given its own grade, so the person actually has six grades, but the highest grade given is used as the Disability Grade for that patient. Grade 0 means no disability found. Grade 1 means that loss of sensation has been noted in the hand or foot (the eyes are not given a grade of 1). Loss of sensation in the hand or foot means that one of the main peripheral nerve trunks has been damaged by leprosy and this is more common later in the disease than at diagnosis. Therefore, measuring and recording grade 1 disability is an essential step in preventing damage to the feet of people affected by leprosy – it is therefore a key component of quality leprosy services. Grade 2 means that visible damage or disability is noted. For the eyes, this includes the inability to close the eye fully or obvious redness of the eye; visual impairment or blindness also gives a disability grade of 2. For the hands and feet, visible damage includes wounds and ulcers, as well as deformity due to muscle weakness, such as a foot drop, or a claw hand. Loss of tissue, such as the loss or partial re absorption of fingers or toes is a late sign in leprosy, but it also gives a disability grade of 2 for that hand or foot[ 6,9,10].

**For effective POD, what are the essential recording and reporting requirements?** The assessment of a new patient, or someone who has already started or even completed treatment, aims to identify potential problems as quickly and as easily as possible. Some of the

measurements or findings of this assessment must be recorded for two reasons: firstly, by referring to previous records, any change or deterioration in the clinical condition can be identified and appropriate treatment can be started; secondly, certain measurements that have been recorded can be compiled into various indicators, which will be reported and used to manage and evaluate the program, and secure the necessary ongoing resources. The amount of information that can be gathered varies greatly. In some places, enough data is collected to complete the Impairment Summary Form (ISF), which allows a high level of clinical monitoring and reporting. In many places at present, however, very little is recorded – often just the presence Grade 2 disability in new cases, which is inadequate, as it does not identify those with loss of sensation and therefore at risk of further disability. Loss of sensation in the sole of the foot (Grade 1 disability) has already been mentioned as an essential measurement for proper case management, namely, a decision about footwear. Grade 2 disability alone is a very poor indicator of change or deterioration so cannot serve as a tool to monitor POD activities. [9, 20, 21, 26,].

**Global burden of leprosy disability:** The WHO elimination strategy (elimination of leprosy is defined as reducing the registered prevalence of leprosy to less than 1 per 10,000 inhabitants), based on the widespread implementation of multi-drug therapy (MDT), has led to a dramatic reduction of the prevalence of registered leprosy. The impact of MDT on the prevalence of leprosy is due to the greatly reduced duration of treatment. The global registered prevalence of leprosy at the beginning of 2007 stood at 224,717 cases, while the number of new cases detected during 2006 was 259,017. During 2006, the number of new cases detected fell globally by more than 40,019 cases (13.4%) when compared with 2005. Since 1985, prevalence of leprosy has been reduced globally by more than 90% and over 14.5 million patients have been cured through multidrug therapy[ 8,11,12]. According to WHO, in 2008 for which record were 249 007 new cases of leprosy, 94% of which were from 17 countries. The figures are dominated by India with 134 184 new cases, down from 473 678 in 2002. It's a very substantial decrease note that, "it doesn't seem biologically possible." Several countries reported increases over the same period. Whenever leprosy surveys have been done in many more cases have been found. Experts fear that many new cases are not being detected, with resultant delays in treatment, increases in transmission, and the development of disabilities. In the 1960s, the worldwide prevalence of leprosy was roughly 11 million cases. There have been enormous improvements since then, but

contrary to the impression left by talk of elimination, the disease is not going to disappear. Instead, numbers are likely to stabilize. The term elimination was commonly misconstrued as meaning eradication. “Countries had their budgets totally cut because the Ministry of Health said that leprosy had been eliminated.” Potential researchers have been discouraged from studying the disease; and political pressure to attain elimination status has seemingly led some countries to manipulate leprosy statistics.” a vaccine for leprosy is not foreseeable, nor necessarily desirable, given the disease’s rarity. If knowledge of leprosy starts to fade, there will be problems with diagnosis: there is no simple test for infection, and even now misdiagnosis is not uncommon. The 35% reduction in grade 2 disability target encourages early diagnosis and efficient case management, and shares the aspiration of the Millennium Development Goals of reducing disease burden.[1,9,14,29,30 ].

**Trend of grade-2 disabilities among new cases:** According to WHO reviewed report .the trend of grade-2 disabilities in all the three formats, both independently and in relation to new cases, was examined. While grade-2 disabilities as a proportion among new cases was highest in China followed by Myanmar, Ethiopia and Madagascar, the indicator viewed as an absolute number was found to be highest in India followed by Brazil and Indonesia, which is due to the large number of new cases detected annually. The grade-2 disability rate among new cases per 100000 populations, which is the target indicator, was the highest in Brazil followed by Mozambique and the Democratic Republic of Congo. In almost all the countries that were reviewed a reduction in the grade-2 disability rate was seen. However, this was less apparent with the proportion of grade-2 disabilities. In countries where the control program was performing consistently well, such as in Thailand and Viet Nam, the new case detection rate and the new cases with grade-2 disability rate are seen to be declining in parallel.[1,9,10,12,13,28].

**National burden of leprosy disability:** The national registered cases of leprosy at the end of June 2007 is 4,611, while the number of new cases detected during 2006/07 (1999 EC) is 4,187. The prevalence rate of registered cases of leprosy, therefore, stood at 0.6 per 10,000 inhabitants at the end of June 2007. However, the registered prevalence varies considerably from region to region. The proportion of children and disability grade 2 among newly detected cases during 2006/07 (1999 EC) is 7% and 10% respectively [1,6, 9]. According to Ethiopian Ministry of

Health routine surveillance data the national proportion of Grade II disability for the last three years in EFY 2000, 2001 & 2002 are 9%, 7% and 9% respectively[3].

**What does it mean to “reduce further the burden of leprosy?”** The “burden of leprosy” can be looked at in three ways: Firstly, the most relevant epidemiological measure of the burden of leprosy is the incidence of disease, which is the number of people developing leprosy during a set period of time, usually one year. Because incidence is difficult to measure directly, the ‘Case Detection Rate’ is used as a proxy for incidence rate. It seems likely, however, that some new cases never come for diagnosis and treatment, so the number of cases detected is lower than the number of incident cases. The global incidence rate of leprosy seems to be declining slowly but the decline is faster in some areas than in others; in a few places the incidence rate seems to be rising. Changes in incidence take place slowly, over decades, and are related to factors such as immunization with BCG and economic development, as well as good leprosy control practices. By this measure, the “burden” of leprosy is declining slowly but new cases will continue to appear for many years. Thus, diagnostic and treatment services need to be maintained. Secondly, the burden may be related to the registered prevalence of disease, which is the number of people on treatment at a certain point in time. The prevalence of leprosy has decreased throughout the world over the last 20 years because of multi-drug treatment (MDT) provided through the Leprosy Control Program. By reducing the duration of treatment to just one year or less, MDT has greatly reduced the numbers on treatment at any one time and hence the “burden” on the health services. Although registered prevalence was a useful indicator to achieve the leprosy elimination milestone, it is not an adequate indicator to reflect changes in the epidemiological trend of leprosy. The third way in which the “burden of leprosy” can be viewed is through the eyes of affected people themselves. Leprosy complications can lead to disability of the hands and feet and sometimes also to blindness. These physical problems are often overshadowed by the social rejection and mental suffering caused by the stigma that persists around this treatable disease in many Communities. It is estimated that more than three million people are living with disability from leprosy. Much of this disability can be prevented and the new Global Strategy calls for increased efforts to reduce this “burden” by preventing disability in new cases, by helping to rehabilitate those with disability and by fighting stigma wherever it exists[2,9,14,15].

There are evidences of associations between age, sex, clinical form, number of damaged nerves at the beginning of treatment, bacteriological index and adopted treatment in the determination of the probability of occurrence of disabilities [22, 23]. Various factors might be associated with the presence of disabilities. For example, differences in disabilities status at registration have been observed with respect to gender, age at diagnosis, and leprosy type according to clinical classification systems or the WHO paucibacillary / multibacillary (PB/MB) classification. At the same time, higher proportions of MB cases amongst male patients have been documented and different age distributions for new PB and MB cases were reported [ 21].

**How can confirm reactions and neuropathies are treated as early as possible?** Many Studies revealed that Reactions and neuritis occur in about 10 – 30% of leprosy cases. Steroids are 50 – 70% effective, but are ineffective if more than 6 months have elapsed since the most recent acute episode. For this reason, it is important that treatment is started as soon as possible. Other studies shows Patient education and awareness are important for early self-reporting of reactions and neuritis. Structured education is needed at both diagnosis and at treatment completion. Regular nerve function assessment is the most effective intervention in the field for the early detection of neuritis, and depends on careful training of the health staff. Where regular nerve function assessment cannot be carried out routinely on all patients, it is helpful to identify high risk impairment or a current reaction, MB patients and post partum women. Difficulties commonly experienced in the field include the high work-load of the health worker, limited access to steroid treatment, and poor uptake even when treatment is available. Weak referral systems mean that few eligible patients benefit. More stringent supervision will help to identify and address these problems. Best practice occurs when health workers have appropriate training and are aware of the importance of treating neuritis; a well organized referral system is essential, as many cases cannot be managed in the peripheral health units. The longer the delay between the appearance of the first symptoms of leprosy and the start of treatment, the more likely it is for nerve damage to occur. For this reason, every effort should be made to inform the public that the early diagnosis and treatment of leprosy prevents the occurrence of long-term complications [16,17,18,19,20].

**Other factors of Disability in leprosy:** studies revealed that an uneven spatial distribution of leprosy and disabilities can be caused by the influence of geography on the distribution of risk

factors over the area or the population characteristics that are heterogeneously distributed over the area. The true incidence of leprosy disease is difficult to measure, and the rate of leprosy infection in a community cannot be measured, Therefore the actual case detection rate provides the most helpful estimate of leprosy burden, The rise in the annual case-detection rate could reflect improved leprosy control and case finding activities in endemic countries, rather than an increase in leprosy incidence. Further observation is needed to show whether long-term implementation of MDT program leads to the predicted fall in the incidence of leprosy disease. Because leprosy is a disease with a long incubation period—10 years may pass from infection to manifestation of symptoms—it is essential that case-finding efforts are maintained if elimination is to be sustained. The social stigma of the disease, which stops patients from seeking treatment, is another barrier that must be overcome to sustain elimination [27,28, 29]. The proportion of new patients with visible disability, such as skin ulceration or muscle wasting and contracture, varies between countries and is affected by the type of leprosy and delay in diagnosis. An estimated 3 million leprosy patients have completed MDT and have sustained disability from nerve damage; these patients need continuing care to limit further secondary damage [26,27,28].

In Ethiopia there are limited studies on the issues grade 2 disabilities. However, detail understanding of the status of grade 2 disability is essential to understanding of risk factors for effective prevention of disability. Research to address issues regarding coverage (assessing patients at the time of diagnosis and on completing treatment), validity and quality of data (whether grade 0 is reported or assumed, grading criteria) and interpretation of indicators in terms of individual impairment status will be needed to be investigated. Absence of reliable data and lack of research have added to the problem. Programs and services dealing with leprosy will continue to need input from research to inform policy and management. Therefore, Solid analysis of the existing disability status is required to devise for the enhanced global strategy for 2011–2015 emphasizes reduction of the number of cases with grade-2 disabilities. [8,9,20,27]



### **3. OBJECTIVE**

- To assess the disability status of new leprosy patient diagnosed between 2000EFY to 2002 from record in Bisidmo Hospital, East Harage.

#### **Specific Objectives**

- To determine the magnitude of Grade II disability among leprosy patient
- To identify factors contributing to disability among recorded leprosy patient

## 4. METHODS

**4.1. Study area:** The study was conducted in Bisidimo Hospital, East Hararge Zone, Oromia. The main town of zone is Harar city located in eastern Ethiopia about 525 Km away from Addis Ababa. The zone has eighteen woredas and the climate is mixed range between 12.6 Co & 35 Co. A total population size of East Harage is 2, 77390. (CSA Ethiopia 2007). The major ethnic groups are Oromo, Amhara, and Somale, most of economically active peoples are engaged in agriculture in the rural and small scale trade in the urban. Health coverage of the zone is 83 % and the distribution of health facilities in the zone are 5 hospitals, 42 Health Centers, a few private clinics, and 165 health posts serving the zonal population with promotive , preventive and basic curative services. Bisidimo Hospital is locate in Babile woreda around 20 Km away from the main city of East Harege. the woreda composed of 47153 male and 46521 female of the total 93,673 population. This Hospital is well known for provision of leprosy services with in East Harege. The study was conducted from Dec. 2010 to April 2011 in East Harage when ethical clearance was secured.

**4.2. Study Design:** Quantitative and Qualitative study designs were used. The Quantitative design was cross sectional record review of all individual patients registered within the last three years period (2000-2002EFY). Subjects diagnosis, disability status, socio demographic and clinical factors were reviewed from the records. Individuals were not fully recorded as having leprosy and disability grade excluded. Relapse and defaulter cases also excluded. The record review was supplemented by qualitative part to understand possible factors contributing to grade 2 disabilities. Since the review of the record could only provide limited information; the qualitative part allowed understanding the factors contributing to disabilities in leprosy cases in the study population. The qualitative design involved in depth interviews, and key informants. Ten in depth interviews, and two key informant interviews were conducted. For in depth interviews persons who were visiting for service and admitted at Bisidimo Hospital for treatment of disability in leprosy symptom at the time of data collection, suitable and capable of being interviewed and were being willing to cooperate in the research included. New cases, Relapse, defaulter and treatment completed were included. But leprosy patients who were seriously ill & incapable of communicating were omitted (for example, age less than eighteen years and deaf people were excluded). A total of 12 clients participated in the interview.

#### 4.3. Source population

The source populations are all leprosy cases recorded in Bisidimo Hospital.

**Study Population:** The actual study unit was each cases of leprosy recorded in Bisidimo hospital from July 2000 -2002EFY those completely recorded cases was reviewed at time of data collection.

#### 4.4. Sample Size and Sampling

As both quantitative and qualitative study designs were employed for this study, two sampling procedures were used. For quantitative method: In the zone a list of government health facilities obtained. Bisidimo hospital is the only hospital reporting with high burden of leprosy cases. Sample size (n) is and calculated manually using single population proportion formula for finite population with 95% confidence interval, the prevalence of grade 2 disability (p) is 10% and marginal error (d) of 2%.

Where

$$n = (Z / 2)^2 P (1-P) / d^2 = (1.96)^2 \times 0.1 (1- 0.1) / (0.02)^2 = 0.345744 / 0.0004 = \underline{864}$$

N= number of leprosy cases recorded in the hospital (2000 to 2002EFY) =568+528+437=1533

Z= the standard score (critical value) corresponding to 95% confidence level = 1.96

d= the proportion of sampling error between the sample and the population = (0.02)

P= the prevalence of grade 2 disability (p) 10%. P is taken from the 2007 grade 2 disability 10 % annual leprosy data, FMOH [ 6]

While the determined sample size was **864** in order to ensure more accurate finding all recorded cases of leprosy was included. For this reason the three years (2000 – 2002 EFY) recorded leprosy cases in Bisidimo Hospital based quantitative study 1512 cleaned data were included.

For the qualitative design: purposive sampling was used to select participants for the in-depth interview and key informants, believed to give adequate information on the study problem were selected. For in depth interview 10 clients were involved, and for key informants interview two health workers were selected in consultation with responsible persons in the organization. A total of 12 informants participated. Two key informant's interview and ten in depth interviews were conducted.

## **Variables of the study**

### **Dependent Variable**

**Disability Status:** based on world health organization disability grade definition, disability grade II was the dependant variable of the study.

### **Independent Variables**

#### **Socio demographic factors**

Age, sex,

Residential

#### **Clinical history:**

Method of case finding,

Characteristics of lesion, sign of nerve damage,

Leprosy reaction, and

Leprosy type according to clinical classification systems of the WHO  
paucibacillary / multibacillary (PB/MB) classification)

#### **Health facility factors:**

Accessibility of health facility (distance of health facility)

#### **4.5. Data collection Procedure**

Once ethical clearance was obtained from university of Gondar and Addis Continental Institute of public health Ethical Review Board, study sites were approached and requested permission to conduct the study. Data were collected at Bisidimo Hospital using combination of methods. One thousand five hundred twelve new recorded leprosy patients were reviewed using structured check lists from patient records.

Open ended semi structured topic guide prepared in afan Orom language was the tool that was used to collect the qualitative data. Semi structured topic guide includes socio demographic characteristics of patient with disability in leprosy and other questions on possible factors contributing for disability in leprosy such as 'Knowledge about leprosy and disability, attitudes, 'Self coping of disability in leprosy cases and support condition', 'income and disability' 'the effect of stigma on disability prevention' educational status, employment status health facility factors, stigma, POD activities, etc.(See annex) Semi structured topic guides were used to gather the qualitative data. The tools have been developed by reviewing relevant literatures and documents.

The qualitative data were collected by in-depth interview, and key informant interview. Ten in-depth interviews and two key informant interviews were conducted, moderated by the principal investigator with the help of an assistant. Interview with their respective respondent were held in quiet halls. Each interview was tape recorded not to miss all issues discussed and to facilitate data collection and analysis, and finally the principal investigator transcribed the tape recorded after each session, translated and interpreted. The key informant interviews were carried out with health care providers at their office in Bisidimo Hospital with three knowledgeable and experienced leprosy service providers. The in-depth interview also carried out with individual of disabled leprosy patient at TBL clinic in Bisidimo with ten disabled patient admitted for care while the key informants were undertaken with service providers in TBL department. Semi structured topic guides with probing questions prepared in Afan Oromo language were the tools used for collecting the qualitative data. The key informant interviews and in-depth interviews were held in Afan Oromo since it is the language used in the region Oromia, and a non directive approach was employed to maximize the richness of the information. In depth interviews took a

minimum of 28 minutes to a maximum of 34 minutes and the key informant interviews took minimum 37 minutes and maximum of 42 minutes. This was to help data collectors easily communicate with respondents and hence to get quality data. A none directive approach was employed during the in depth interview and key informants to maximize the richness of the information.

For the quantitative study of record review, five data collectors (nurses) and two supervisors were recruited for record review process. These data collectors and supervisors received training for one day the training has equipped data collectors and supervisors with the necessary knowledge and skills on administering the questionnaire/ check lists and on their responsibilities in general. This has been witnessed during role plays, by gathered data. Data were gathered from recorded cases of new leprosy diagnosed between 2000EFY to 2002EFY from patient cared, leprosy unit register and leprosy registration book using check lists prepared in English language hence, the available data were written in English. Data collectors were closely supervised by the supervisors and principal investigator.

#### **4.6. Data quality**

All data collectors have attended a short training on both qualitative and quantitative research methods issues like interview techniques, establishing rapport, neutrality and recording the answers precisely as they are provided without shifting or interpreting them were well dealt. The semi structured topic guide was used as reference for interview and discussion. The training was facilitated by the principal investigator. Additional support has been provided during supervision and the regular daily meetings. None directive approach was employed during the in depth interview and key informants to maximize the richness of the information. Semi structured topic guides were used to gather the qualitative data. The tools have been developed by reviewing relevant literatures and documents.

Supervision on the process of record review particularly proper implementation of tools has been done regularly by the principal investigator. The principal investigator assessed daily collected data for completeness and internal consistency of the data was checked during data processing and finally the data was reviewed during the analysis for consistency.

#### **4.7. Data Analysis procedures**

For Quantitative method: The three years of records of leprosy cases was analyzed. Only cases were with definitive gross diagnosis for leprosy was included. The age, sex, type of lesions and sign symptom of grade 2 disability was extracted from the recorded data of the identified cases. The data was entered using EPI Info version 3.5.1, exported and cleaned using SPSS version 15 and analyzed by SPSS and EPI Info. The data was summarized and presented by frequency tables and summary statistics and presented by graphs, tables and other summery measures. For all statistical significance tests, the cut- off value set is  $p < 0.05$  as this considered statistically reliable for analysis of this study. The factors associated with increased risk for grade 2 disability at the time of diagnosis was analyzed both separately and in combination. In the data analysis, an odds ratio for risk factors for presentation with grade II disabilities at diagnosis was calculated using bivariate and multivariate logistic regression. The significance of the associations was presented by crude and adjusted odd ratios and the 95% confidence interval.

Qualitative method analyzed to developing concepts which helps to understand social phenomena by giving due emphases to the meanings, experiences, and views of all participants. data analysis was done manually, included immersion, coding, explore thematic area, interpret data to search core meaning, simple Summary of response of individuals about each theme described and over all interpretation of finding was done. The notes from in-depth interviews and the key informant interviews were read and screened for common themes discussed during the interviews. Then results were screened for common themes discussed during the interviews. The results were then categorized according to these themes. The themes were 'Knowledge about leprosy and disability', 'income and disability' , 'Self coping of disability in leprosy cases and support condition', 'the effect of stigma on disability prevention', ' health facility factor' and for the key-informants, 'patients knowledge about prevention of disabilities and leprosy', and POD activities from the prospects' of these persons. The representative answers were described in the result was accompanied by relevant quotes, and the narration of the report was done.

#### 4.8. Operational Definitions

**Disability:** "an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and the individual's contextual factors (environmental and personal factors)" [9]

**Impairment:** “problem in body function or structure such as a significant deviation or loss.” [9]

**New case :** a patient with MB or PB who has never received treatment for leprosy before.

**Prevention of disabilities (POD) :** defined as ‘a concept comprising all activities at individual, community and program level aimed at preventing impairments, activity limitations and participation restrictions’. [9]

**Prevention of worsening of disabilities (POWD):** Interventions that are aimed at preventing the worsening of disabilities or deformities already present when the disease is diagnosed.[9]

**Disability Grade:** shows the condition of the patient at diagnosis. The grade is 0, 1 or 2. Each eye, each hand and each foot is given its own grade, so the person actually has six grades, but the highest grade given is used as the disability status for that patient.[6]

Table 1 Classification of disabled grade of leprosy by WHO.

Grade	Hand and Feet	Eyes
<b>Grade 0:</b>	No disability found There is no anesthesia or visible deformity or damage.	no disability found. No eye problem due to leprosy, no loss of vision.
<b>Grade 1:</b>	loss of sensation has been noted in Palm of hand or sole of foot, but No visible deformity or damage	The eyes are not given a grade of 1.
<b>Grade 2:</b>	visible deformity or damage present. This includes wounds and ulcers as Well as deformity such as foot drop or a claw hand.	Visible damage or disability is noted. this includes redness of eyes, visual impairment or blindness (inability to Count finger at 6 meters)



#### **4.9 Ethical consideration**

An approval from the ethical clearance committee of Addis continental Institute of public Health and University of Gondar secured. Letter from Oromia regional health bureau obtained for the respective authorities and the letters were delivered to East Hararge Zone health department and Bisidimo Hospital and permission obtained. Lastly verbal consent obtained from individual participants for qualitative study. Information on the study to be conducted and consent form prepared and presented to each individual participant. They informed about the issue of confidentiality and that they had full right to refused or discontinued participating in the research without any compromise in the service they got from the respective facilities, hence, the study subjects was participated voluntarily in to the qualitative study.

Once the necessary permission to undertaken the study from the responsible authorities a copy letter was informed the East Hararge Zonal health department and Bisidimo Hospital. For quantitative method the information was collected through reviewing secondary data in the recorded cases of leprosy and assured that the privacy and the confidentiality was strictly secured throughout the study. All clinical and socio demographic information numbered and coded and the name was not used throughout the research process. And informed as a report of results only information about the total group will appear and finding of the study will be communicated with the hospital for practical utilization.

## 5. RESULTS

### 5.1. Quantitative part (record review)

**Profile of the new record cases of leprosy:** A total of 1531 recorded new cases were enrolled in the Bisidimo Hospital. Out of these, 19 individuals were not fully recorded as having leprosy and disability symptoms and socio demography. Thus, 19 new cases had to be excluded from the present data analysis. This paper reports on the resulting 1512 newly detected patients from 2000 - 2002 EFY of Bisidimo Hospital recorded case. The 1512 included patients and the new cases detected in the EFY 2000 to 2002 period by Bisidimo Hospital's routine control program records were reviewed for age, sex, leprosy type according to clinical classification systems of the WHO paucibacillary / multibacillary (PB/MB) ,type of leprosy bacteria, leprosy reaction, distance of patient residences to Bisidimo Hospital and WHO disability grades. Important discrepancies were not observed, and the patients involved in this study were thus considered to be reasonably included all recorded new case detected by Bisidimo Hospital in the same period.

Out of the patients involved in this study, 99.9 % reported voluntarily. This confirms the passive nature of case finding by Bisidimo hospital's program in the 2000 EC – 2002. The number of males in the study population was almost three times as high as the number of females (male to female ratio: 3:1). The child proportion was 5.7%, and the highest group of the patients was age between 30 - 44 years consists of 32.8% and 34.8% of grade two disabilities were among this age group. The most common clinical classifications were MB 1430 (94.6) and 82(5.4%) PB cases were seen. Among disability MB cases accounted 99.6% of grade 2 disabilities and only 0.4% of cases resulted in PB. Skin smears were taken from all among which 39.1% positive and 60.9 % were negative for AFB. Only 23.1% of grade 2 disabilities were positive for skin smear and 74.9 grade 2 disabilities were negative for skin smear. The median distance was 70 KM from patient's residence to Bisidimo Hospital. Only 17.6 % of patients had leprosy reaction.

**The magnitude of Grade II disability:** Leprosy induced disability are very common in the study population among which 18.3% (95% CI= 16, 20) new patients presented with visible physical impairment (WHO Grade II disability) ,diagnosed at Bisidimo Hospital in 2000-2002 EFY. The three year trend of new leprosy cases at 2000, 2001& 20002EFY were 17.4%, 20% and, 17% respectively. The trend show no comparable decrement rather fluctuates. Increment is showed during 2001 EFY. (See fig.1)

### Factors contributing to disability

The study analyzed the association of different variables with grade two disabilities. For data analysis, patients were re-classified according to a composite classification with different categories. Disability grade II was compared by patient sex, age, residence, clinical classification systems of the WHO paucibacillary / multibacillary (PB/MB) classification.) Leprosy reaction and distance of the patient residence to hospital to see if differences exist between those grade two disabilities risk factors. Association could be detected between grade II disabilities and age at different group, residence of the patient, reaction of leprosy and type of leprosy bacteria in crude analysis, and this association was maintained in multiple logistic regressions except for type of leprosy bacteria. Sex of the patient and the distance of patient residence were not associated with grade two disabilities. Age group 30-44 years AOR (95% CI) 2.363(1.026, 5.442) , age group 45 – 59years AOR(95 CI) 3.904(1.664, 9.158) and age group 60+years AOR (95%CI) 3.978(1.651, 9.588) show the risk of grade two disability increased with age. Leprosy with reaction has higher risk of getting grade two disabilities than patient without leprosy reaction AOR (95%CI) 1.562(1.108, 2.203). (See table 2)

Figure. 1

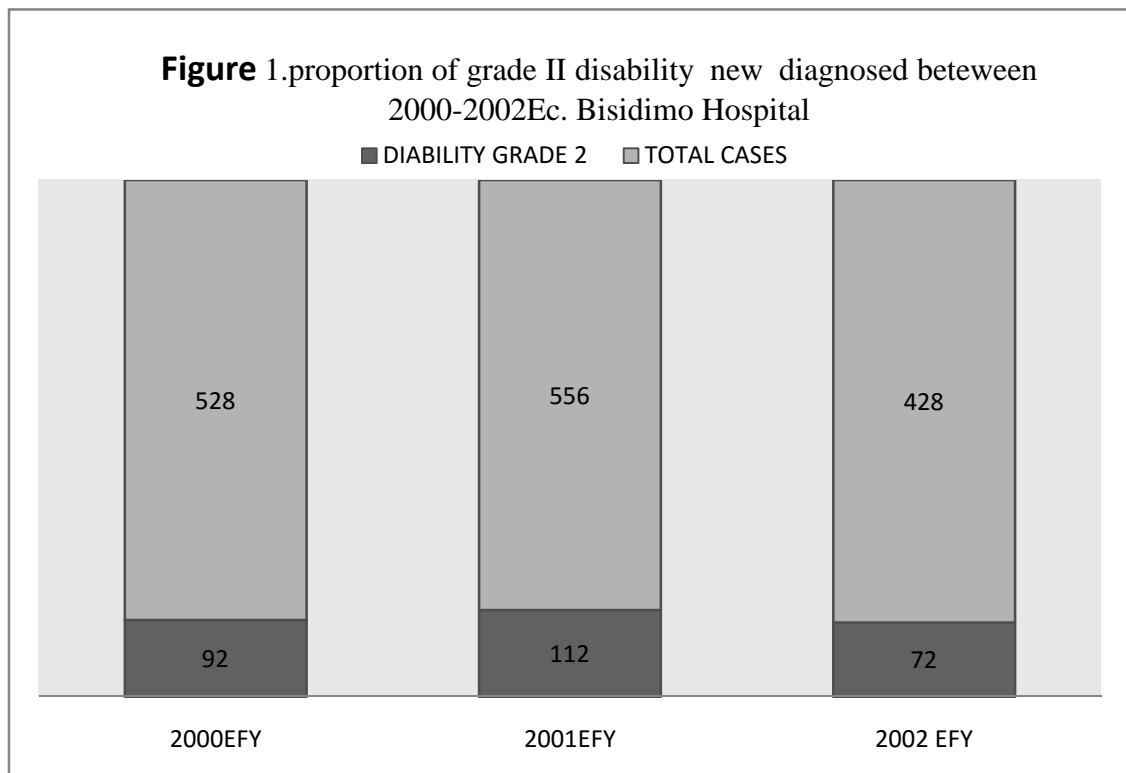


Table 1 Proportion to the numbers of patients for which information is available.

Factors	frequency	percent
<b>Sex</b>		
M	1144	75.7
F	368	24.3
Total	1512	100
<b>Age</b>		
0 - 14 years	86	5.7
15-29years	538	35.6
30-44 years	496	32.8
45 – 59years	235	15.5
60+years	157	10.4
<b>Patient Residence</b>		
Urban	38	2.6
Rural	1449	97.4
<b>Total Method of case finding</b>		
Voluntary	1504	99.9
Contact	1	0.1
Survey	0	0
<b>Types of leprosy</b>		
MB	1430	94.6
PB	82	5.4
<b>Leprosy reaction</b>		
Yes	259	17.6
No	1216	82.4
<b>Disability grade II</b>		
Yes	276	18.3
No	1236	81.7
<b>Distance (Km)</b>		
< 10Km	29	2
11 -25 Km	92	3
26-100 Km	819	56.0
>100 Km	522	35.7

**Table 1:** WHO Grade II disability at diagnosis and factors associated with it.

Factors	No. of Grade 2 Disability (% of all cases)	COR (95% CI)	AOR (95% CI)
<b>Sex</b>			
F	76/368 (27.5)	1	1
M	200/1144 (72.5)	1.228(0.915, 1.650)	0.773(0.563, 1.062)
<b>Age</b>			
0 - 14 years	8/ 86 (9.3)	1	1
15-29years	63/538 (11.7)	1.293(0.597, 2.803)	1.339(0.577, 3.110)
30-44 years	96/438 (21.2)	<b>2.340(1.093, 5.008)</b>	<b>2.363(1.026, 5.442)</b>
45 – 59years	64/235 (27.2)	<b>3.649(1.669, 7.978)</b>	<b>3.904(1.664, 9.158)</b>
60+years	45/ 157 (28.6)	<b>3.917(1.750, 8.768)</b>	<b>3.978(1.651, 9.588)</b>
<b>Patient Residence</b>			
Urban	17/38 (44.7)	1	1
Rural	252 /1449 (17.4)	<b>0.260(0.135, 0.500)</b>	<b>0.597(0.165, 0.685)</b>
<b>Leprosy reaction</b>			
No	208/1216 (17.1)	1	1
Yes	64/259 (24.7)	<b>1.591(1.156, 2.189)</b>	<b>1.562(1.108, 2.203)</b>
<b>Distance (Km)</b>			
≤ 10Km	3/29	1	1
11 -25Km	16/92	0.448(0.133, 1.507)	0.400(0.090, 1.780)
26 -100Km	138/819	0.817(0.457, 1.458)	0.713(0.381, 1.333)
> 100Km	107/522	0.786(0.594, 1.040)	0.785(0.584, 1.055)

## **5.2. Result of the Qualitative study**

The notes from in-depth interviews and the key informant interviews were read and screened for common themes discussed during the interviews. The results were then categorized according to these themes. The themes were 'Knowledge about leprosy and disability', 'income and disability', 'Self coping of disability in leprosy cases and support condition', 'the effect of stigma on disability prevention', 'health facility factor' and for the key-informants, 'patients knowledge about prevention of disabilities and leprosy', and POD activities from the prospects' of these persons. The representative answers are described in the results.

### **Factors contributing to disabilities**

**Knowledge on leprosy and disability prevention:** The entire in-depth interview participants do not have knowledge on leprosy mode of transmission and the majority of interviewed participants indicated that disability is considered a punishment from God "Disability comes from Allah's will. We don't have the power to reject it."

Other respondents believed that Leprosy is considered to be a hereditary or transmitted disease, but also one that can be caused by a curse. One 22 years male interviewed said "Leprosy tends to occur within families, really it is hereditary my father was leprosy he passed away before five year and I have got leprosy within the last six months this shows that inter generational curse ." The in-depth interview participants said, during their stay in Bisidimo Hospital as they heard health education on the mode of transmission of leprosy and prevention of disability but couldn't realize. They believe everything capable of making disabled even death is happened on the choice of God. One 56 old male respondents said, "The cause is curse, if it is a curse, there is no cure for the disease, the person who has it and his family will feel very humiliated. For me it is the order of Allah's being I am disabled". People do feel that comfortable because it is curable if you bring him / her to "Sheka'(kind of traditional healer who's an influential in religious issues to cure)" and provide 'duea' (a kind of pray) and 'wodaga' (it's a kind of pray in group)." this shows that the existence of Various beliefs about people with leprosy and disabilities, that first sought help from traditional healers instead of directly contacting the health services. The majority of discussants had foot ulcers during admission. They didn't have knowledge on the importance of choosing footwear that gives good protection and they could not avoid walking for

long distances, and they didn't had any knowledge how to take care their feet daily and cleaned.

For example, a key informant said: "About leprosy and disability usually new diagnosed patients think that as the cure is not permanent, people undergoing treatment are contagious throughout their life, clients cannot prevent disabilities even if they accept their own responsibility for doing so, and once a person has been diagnosed they should not continue to live as normally as possible" generally the knowledge, attitudes and behavioral change to ward leprosy and disability prevention were very poor.

The key informant's expressed the same response on the disabilities associated with knowledge of leprosy patient "Appropriate health information was given to all patients but they could not accept easily because of their harmful beliefs". Majority of newly diagnosed cases of leprosy patient presented with an anesthetic hand or foot but none of cases understand the importance of daily self care, especially protection when undertaking potentially dangerous tasks, and inspection for trauma. But a number of cases come again with developing further disability this related with lack of self care in hand and foot ulcers when patients are back to their catchment and home. Almost all new patients' self-awareness is very poor so that damage is common. This shows that disabilities resulted in lower Knowledge.

**The effect of income on prevention of disability in leprosy:** All in-depth interviewed participants with grade II disability in leprosy are very poor already, and it exacerbates their disability in several ways they have insensitive hands and feet, they can injure themselves by carrying out the heavy manual labour generally associated with unskilled heavy work especially agricultural activities and weight-bearing. None of the interviewed had employed. They said that they did not have a reasonable chance to get a paid job. They indicated that lack of proper education and of suitable vacancies were reasons for this. The leprosy disabled are unable to work quickly; they experience the most problems with heavy activities. All disabilities related to leprosy are suffering more severe problems related to their condition they usually have severe disabilities making it impossible to work. One respondent said: "I can't generate money for a living".

All interviewed participants agreed that their disability was their biggest barrier to find a job. One 45 year old female in depth interviewed patient with both feet disabled said “ I am dead you know disability in leprosy is a living death” the majority of interviewed patient expressed their opinion as disability in leprosy has many terrible effects on their life. One of the male interviewed said "I was treated but not cure, I forced to be deformed and hopeless for the rest of my live". Almost all interviewed agreed that their physical disabilities which contribute to social stigma resulting in hopeless and unproductive to work and poorer. This shows that disability in leprosy remains as closely associated with poverty.

**Self coping of disability in leprosy cases and support condition:** The in-depth interviewed participants experienced exclusion from social activities held at community-level. None of the leprosy disabled received support from their community in the prevention of disability. Some interviewed suffering leprosy-related disabilities did not live with their families any more. One respondent said: "Right now, it is far different than when I was healthy. In former times, I was living with my husband and children having loved each other and I was hope full even if my living standard was very poor, my home rural it was far away. Now not anymore, my husband married healthy women. I will never back to there. Now I suffered with cures of an event and my foot is amputated." She totally prefers to live at Bisidimo Hospital than her host home. From most of interviewed explanation concerning on their social support for their disabilities very weak, governments can provide little economic support. Considering the exacerbation of further disability, avoiding physically damaging job for people disabled by leprosy is encouraged. In reality they could not avoid physically damaging job. This revealed that lack of supports worsen disabilities in leprosy.

**The effect of stigma on disability in leprosy:** The in-depth interviewed expressed that as they were stigmatized with the word ‘leper’ for whoever is feared and hated. Some of the interviewed participants came from where leprosy is common. One of 35 old female said that "Once diagnosed with leprosy, many young women will still give up all hope of marriage." It is difficult for people affected by leprosy to find a partner, except in cases where that partner is affected by leprosy also. The main reason is that people consider leprosy a hereditary disease, so healthy people are afraid to get a descendant with leprosy. It is therefore not surprising that people affected by leprosy continue to hide their condition from their community, their colleagues and



even their family. To avoid discovery, those who can afford to do so will avoid public clinics and pay for private treatment, even travelling to cities where they are not known. Most of interviewed patients bear this burden of secrecy because they feel that the alternative would be worse. Even people affected by the disease will believe many of the bad tradition about leprosy and as a result suffer from low self-esteem. All interviewed gave evidence of the existence of stigma, resulting in social participation restrictions. This shows that disability in leprosy strongly associated with stigma.

**The Health facility factor:** Different responses were observed on this theme some of them stated that for most community's leprosy services were not available, accessible and not utilized while others mentioned leprosy services available but lack diagnostic capacity. Other added there are communities that had difficulty of access to services because utilization of services influenced by inadequate income and far distance. The entire in-depth interview participant tended to delay seeking care for leprosy. The cost of treatment was not a big factor in the decision to delay seeking care. Each of six participants was charged over 1000 Birr for medication prior to visiting Bisidimo hospital. An average they had spent 1600 Birr for misdiagnosed medication and transportation. The majority of interviewed expressed one to three years delayed for the right treatment of leprosy from the first symptom due you to their poor knowledge and negligence, misdiagnosed and lack of appropriated management from first visited health facility were mentioned. The disabled leprosy patient interviewed said they were quite satisfied with the disability prevention service provided by the Bisidimo Hospital, rating it either excellent or good.

The key informants expressed their opinion as follow: Although they have been treating leprosy with effective Multi Drug Therapy to leprosy patients, they have made far less progress in helping them to prevent disabilities. The majority of leprosy patient diagnosed and admitted for ulcer care in Bisidimo Hospital were from West Harage and East Harages far areas, this might proved very few of health facilities leprosy services have made the teaching of self care importance thus a particular lack had been disability prevention for people who had been infected with leprosy in their catchment areas. This leads for continued flow of leprosy and disability cases to Bisidimo Hospital setting up well systems of disability prevention and care is one of the major challenges still face. In such area in which the concept of leprosy integration

services need to be realized this may reduce the burden of disability in leprosy at Bisidimo Hospital. The key informant also explained the service given to grade II disabled patients as follow "For patient presented with Anesthetic feet we provide protective footwear, but difficulty to screen early and its appropriate utilization for prevention of disability." All ulcers in leprosy admitted and treated as inpatient for ulcer care and at the same time health information is given. Hence the capacity of leprosy service at health facility associated with disabilities in leprosy.

## 6. DISCUSSION

The three year cumulative proportion of 18.3 % grade 2 disabilities observed in this study. Factors age, residence, leprosy reaction, has significant association with disabilities. Other risk factors for which have been identified by qualitative method which were not found in records in the present study include knowledge, income, stigma, employment status and socio-economic factors closely associated with grade II disabilities.

**Magnitude of grade II disability:** The three year cumulative proportion of 18.3 % grade 2 disabilities observed in this study is significantly higher than the national target of less than 5%. The magnitude of the visible problem in new cases is usually expressed in terms of the proportion with grade 2 disabilities in a given year, this indicator reflects the effectiveness of the program in terms of early case finding and the level of community awareness of the disease[2,12,15,16,]. Where the control program was performing consistently well, the new case detection rate and the new cases with grade-2 disability rate are seen to be declining in parallel [1,3,9,28,29].

the proportion with grade 2 impairment reported by somewhat lower in FMOH routine surveillance data in EFY 2000, 2001 & 2002 are 9%, 7% and 9% respectively,[3] considering Bisidmo Hospital presence in the area for a period of over 3 years, EFY 2000, 2001 & 2002 are 17.4%, 20%, 17% respectively. Also the new case detected in this hospital with in EFY 2000, 2001 and 2002 are 528, 566, and 428 respectively. The trend shows fluctuation and slight increment in 2001 EFY. The most recent WHO report revealed, amongst major endemic countries, the proportion of new cases presenting with WHO disability grade 2 was reported in 2010 to range from 1.45% to 22.8%. the proportion of new cases with grade-2 disabilities in the African Region it ranged from 1.45% in Liberia to 20.71% in Burundi; in the Eastern Mediterranean Region it ranged from 6.00% in Egypt to 19.80% in Sudan; and in the Western Pacific Region, Malaysia reported the smallest proportion of new cases with grade-2 disabilities at 4.28% of new cases, and China reported the largest proportion at 22.8%. Annually, around 12 000– 14 000 new cases with grade-2 disabilities are detected globally[1,9]. From this study 18.3% Proportion of grade II disabilities reflects early case finding and the level of community awareness of the disease were low. The new case detection and the new cases with grade-2 disability rate were not declining in parallel with in the study population. with the introduction of

MDT for leprosy, the Prevalence of the disease has sharply gone down, however the notification of new leprosy cases remain constant over the past years and indication that transmission is still going on. From many previous research findings with higher magnitude of grade II disabilities had strong evidence that such higher proportion can be expected when diagnosis is delayed [9,15,16,,20,21,26].

Amongst major endemic countries, the proportion of new cases presenting with WHO disability grade 2 was reported in 2010 to range from 1.45% to 22.8%. the proportion of new cases with grade-2 disabilities in the African Region it ranged from 1.45% in Liberia to 20.71% in Burundi; As many evidences revealed that Integrated leprosy control services have played an important part in the prevention of disabilities, in many countries where the disease is endemic, those countries case detection improved, significantly reduced the proportion of grade two disabilities [1,9,25,26]. But in Bisidimo hospital cases of leprosy were coming from far such as West Hararge woredas and East Hararge woredas. From all 1512 diagnosed cases of leprosy only 21 of cases were the catchment of Bisidimo hospital, this may be one reason that absence of the diagnosis and prevention of disability at local health facility. In fact, referral centers that are part of the general health-care system have been crucial in helping primary care services deal with complications, prevent disabilities and provide rehabilitation [1,2,6,24,25,26 ]. The median distance of the study population was 70 KM from patient's residence to Bisidimo Hospital, all cases of the study population (99.9%) of new cases were reported voluntarily and no cases were referred in to Bisidimo Hospital and patients were referred out to the nearest facility for registration and treatment after diagnosed and getting the required care. The proportion with grade two disabilities was similar for different KM distances. The multivariate result indicates that even with in the radius of 10 KM distance to hundreds KM distance and between the presentation of grade II disabilities are not associated. Therefore for the current integration on leprosy service at different level of local health facility in East & west Hararge should be investigated.

The finding of this study was leprosy patients diagnosed very late in their illness as shown by 18.3% of grade 2 disability. Many researches describes where in the area of higher grade II disabilities, patients are infectious for some time before they are detected, so they are shedding

*Mycobacterium leprae* into the environment for several months. To reduce grade 2 disabilities it needs to be diagnosed quickly [9,25,26,27].

Some studies show that the current strategy is misunderstanding of the elimination concept by decision makes. Many countries on reaching elimination have substantially reduced leprosy control activities, as the case in Zambia. But given that the incubation period is 7–10 years, the number of cases could shoot up again without ongoing control. It would therefore be more useful to look at case detection as a target, to lower the magnitude disability [25, 26, 27, 28]. From this magnitude of grade II disability, highlights the need for continued surveillance for early case detection and the communities' awareness on leprosy disease should be addressed. So that cases of leprosy can be detected before people suffer the long-term consequences of disabilities.

**Age** as a risk factor several studies have reported that the risk of impairment in new cases increases with age [21] In the present study, the multivariate analysis shows that the risk of impairment increases with age independently of other risk factors. Interestingly, a different effect of age was shown for the risk of grade 2 disabilities amongst impaired new cases: this study showed this risk to be lowest among the individuals of ages 29 and below. Additional and another recent WHO report shows did not give further evidence for the finding of a lower risk of grade 2 disabilities in impaired new cases of younger age. On the whole the number of the age below 15 and age between 15 to 29 on this finding was affected in very small when compared to age group greater than 30 years in fact the low numbers of the age group below 15 years infected by leprosy is it seems the transmission is declining. It is therefore possible that adults come into contact with leprosy-infected people in many reasons; it is therefore possible that the age group below 15 is spending their time longer at school thereby reducing their exposure to mycobacterium leprae. The other explanation is that BCG vaccine might be protecting the age group below 15 from leprosy [1,3,8,9,].

**From the risk factor of sex** Males had impairments more often than females, but this finding was neither significant in the bivariate nor in the multivariate analysis. Although with a non-significant difference the proportion of grade two disability from this finding as such that grade two disability is more common in females (20.6%) than males (17.5%). Many researches revealed that male is higher risk of disabilities in leprosy and inconsistent with this study [20, 21, 22]

**Type of leprosy bacteria** The high proportion of MB leprosy observed in the present study is consistent with studies done by [21,22] as this studies in Bisidimo Hospital , it has been shown that the peoples contacts with multibacillary patients were 96.4% that means at highest risk of leprosy while those of paucibacillary contact have a 5.4% .Therefore it has been concluded that paucibacillary leprosy may not be a source of infection but a marker that one has been in contact with multibacillary source of infection. Previous studies have shown that the proportion of people with disabilities at registration, which are mainly attributed to multibacillary leprosy, As is well known that multibacillary leprosy can cause a lot more complications MB patients with had the highest risks of impairment.[9.19,21].From this study MB patients had relatively much developed grade two disability, and had a significantly associated with risk of grade 2 disability with wide confidence interval of 19.286 (2.672, 139.180) showed that this risk was significantly higher only for patients with in bivariate analysis, its Significance disappeared in the multivariate analysis. However, such a multivariate association does not occur in this study from observed bivariate associations between types of leprosy bacteria and grade two disabilities may be confounded by other factors and the number of PB by itself few to compare with the highest proportion of MB.

**Leprosy reaction:** with this study leprosy reaction significantly associated with grade two disabilities AOR 1.52(1.108, 2.203). This finding is consistence with many previous researches. Hence, the prevention of disabilities resulting from the disease is performed by means of early diagnosis and treatment. These reactions are manifestations of the patient's immune system in the presence of the bacillus, and they cause the exacerbation and emergence of new systemic inflammatory processes that may or may not be associated with neuropathy. Early diagnosis and the adequate treatment of leprosy reaction is fundamental to avoid or reduce disabilities [33].

**Risk factor in distance to health facility** this study clearly shows that there is no any association of distance to hospital the disability status of new leprosy patients from 10km radius to hundreds of KM far to Bisidimo hospital. Patients with near to Bisidimo Hospital had similar chance of being disabled with patients with distant to Bisidimo Hospital. Among the cases of grade II disabilities, similar differences were observed and their chance of grade 2 disabilities for distant below and distant above 10 KM. In this study, significant associations with the risk of

impairment were neither found in the bivariate nor in the multivariate analyses. Studies service delivery by near health facility can improve the service of leprosy and decreases the proportion of disabilities. But this finding shows the reverse [1,2,26,27,28]. This may be confounded with other factors.

**Other risk factors** for grade II disabilities which have been identified by qualitative method which were not found in records in the present study include Knowledge, income, stigma, geographic and socio-economic factors, employment status and POD activities.

The interviewed leprosy patient's self-awareness was very poor so that damage is increased. A patient with a loss of sensation hand or foot needs to understand the importance of daily self care, especially protection when Undertaking potentially dangerous tasks, and inspection for trauma.

Studies of self care show a reduction in hand and foot ulcers when patients are trained [12, 18,25]. Other research finding revealed that appropriate footwear for leprosy patients showed that protective for leprosy induced disability because sensory lost feet need protective footwear to avoid ulceration secondary to increased pressure over bony prominences, exacerbated by loss of protective sensation or deformity. The majority of qualitative research participants' residences were far from Bisidimo hospital and they came on foot with weight bearing. These aggravate the foot ulcer. However such patients were mentioned as they had got health education on leprosy during their first visit to Bisidimo Hospital their level of knowledge on self care were very poor. The results showed that most leprosy patient with disabilities encountered many more problems in daily life, mainly due to stigma. It became clear from the interview results that patient suffering leprosy-related disabilities had the most psychological problems caused by their condition.

Studies revealed that, stigma of the leprosy disease, which stops patients from seeking treatment, is another barrier that must be overcome to reduce grade II disability in leprosy. [21,22,26,27,32]. Better health care may improve the condition of all these leprosy related disabilities. However, poor leprosy patients also encounter problems accessing health care. First and foremost, this is caused by the circumstances the poor leprosy patients live in. This study was done in a rural area. Access problems are more severe in rural areas. High rates of illiteracy,

longer distances, bad roads and limited access transportation and like are some of common problem with disabilities. The stigma so often attached to it, persist in all interviewed particularly the rural areas of east Harage. Generally the knowledge, attitudes and behavioral change to ward leprosy and disability prevention were very poor. Almost all interviewed agreed that their physical disabilities which contribute to social stigma resulting in hopeless and unproductive to work. This shows that disability in leprosy remains as closely associated with poverty as ever.

It is evident from the results that something must be done about the knowledge and income regarding disablement in leprosy. More easily accessible POD services must be set up. Such services can give health education, advocate for these disabled in leprosy and improve their income. Efforts must be made to improve the social and economic status of leprosy disabled people. Eventually, this is likely to be one of the most effective ways to improve the quality of life of the leprosy disabled people.

**Strength of the study:** Inclusion of both quantitative and qualitative methods to conduct this study can be considered as the strength as strength of the study. Mix of methods was used to compliment or triangulate the findings. Moreover, the study involved different category of respondent: Grade two leprosy disabled patients and health professionals. Selection bias was minimized in the quantitative study of record review since all recorded leprosy patient were included. The principal investigator collected all the qualitative data. Training and supervision were employed and data quality assured.

**Limitation of the study:** Being record review and hospital based are limitation of this study. It might not show subsequent of patterns of factors it might also over estimate findings as the data were facility based. The hospital is a referral hospital where more severe cases are likely to be seen which might lead to selection bias. Recall biases the other limitation of the study as it purely depends on the responses of the participants in qualitative method. Respondents might likely to choose to answer what the interviewer would like to here. Besides, lack of as many similar studies would limit comparison of the study findings. Secondary data was used which might be incomplete dispute our effort to triangulate different sources. Further more the exclusion of incomplete records might have an implication to the main finding.



## 7. CONCLUSION

The magnitude of the visible problem in new cases is usually expressed in terms of the proportion with grade 2 disabilities in a given year; this indicator reflects the effectiveness of the program in terms of early case finding and the level of community awareness of the disease. This study confirmed that, the proportion of grade II disability is 18.3%, significantly higher than the target of 5%. Action is needed to improve access to appropriate prevention of disability services. Concerning on the three year trend of new cases of leprosy and grade II disability at Bisidimo hospital needs attention and action. Such magnitude of grade II disability highlights the need for continued surveillance for early case detection and the communities' awareness on leprosy disease should be addressed. So that cases of leprosy can be detected before people suffer the long-term consequences of disabilities.

From the qualitative finding disability resulted in lower knowledge , income, for almost all disabled patients' self-awareness were very poor and none of cases understand the importance of daily self care so that damage is not minimized. One thing is clear; disability and stigma are the main concern of people affected by leprosy. Hence, a continuous intervention is a must to sustain elimination and reduction of grade 2 disability.

It is evident from the results that something must be done about the knowledge and income regarding disablement in leprosy. More easily accessible POD services must be set up. Such services can give health education, advocate for these disabled in leprosy and improve their income. Efforts must be made to improve the social and economic status of leprosy disabled people. Eventually, this is likely to be one of the most effective ways to improve the quality of life of the leprosy disabled people.

## **8. RECOMMENDATIONS**

### **1. For policy makers**

Concerning on the three year trend of new cases of leprosy and grade II disability at Bisidimo hospital needs attention and action. Such magnitude of grade II disability highlights the need for continued surveillance for early case detection.

It is evident from the results that something must be done about the knowledge and income regarding disablement in leprosy. One thing is clear; disability and stigma are the main concern of people affected by leprosy. Hence, a continuous intervention is a must for reduction of grade 2 disability.

### **2. For program managers and leprosy service implementers**

- Strengthening self care teaching activities.
- Operational research to address basic POD measures, such as self care of leprosy disabled.
- Awareness creation should be improved.

**3. For researchers:** Large scale study is also recommended to strengthen the finding of this study and to have a broader view on the study objectives. Research to address in the area of prevention of disability and the outcome of diagnosed grade II disability patients need to be assessed.

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## **Annexes**

### **Informed consent form**

**University of Gondar and Addis continental Institute of Public Health**

**School of Graduate studies**

### **Introduction**

**My name is \_\_\_\_\_ working/ student of \_\_\_\_\_.The aim of this study is to assess the disability status of recorded cases of leprosy in Bisidemo hospital. It helps to identify major problems that affect prevention of disability in leprosy patients.**

### **Informed consent for in-depth interview**

**For the selected subject read the following:**

**To help our study, I would like to ask you some questions which I may take about an hour. As your participation is very important to the outcome of the study, we kindly request you to give us your sincere and truthful answer. All your response will be kept fully confidential and your name will not be recorded or mentioned. All your response will not be used for other purpose except for the aim of this study.**

**The information you will give me are very important. I may not capture all the information by my note book. Therefore allow me to use tape-recorder that additionally helps me. You have full right not to participate or withdraw any time in between whenever you feel discomfort.**

**Do you agree to participate in the interview?**

**Yes, I agree\_\_\_\_\_**

**No, I don't agree\_\_\_\_\_**

**Thank you very much**

## **Informed consent for in-depth interview**

### **ጎንደር ዩንቨርሲቲና አዲስ ኮንትነንታል እንስትትዩት**

#### **የድህረ ምረቃና መርሀ ግብር የህብረተሰብ ጤና ክ**

የስጋ ደዌ ህሙማን ለአካል ጉዳተኝነት የሚዳርጋቸውን ዋንኛ እንቅፋቶችን ለመለየት የሚጠቅም መጠየቂያ የፍቃደኝነት ማረጋገጫ ቅፅ

#### **መግቢያ**

ስም ----- እባላለሁ የምስራብት /የምማርበት በ ----- ነው። ሰዎችና የስጋ ደዌ ህሙማን በወቅቱ ወይም በጊዜ ወደ መንግስት የጤና ድርጅት ሄደው ህክምና እንዲያደርጉ ይያግዱትን ምክንያቶች ዙሪያ አንዳንድ ጥያቄዎን እንጠይቃለን። የዚህ መጠይቅ አላማ የስጋ ደዌ ህሙማን በወቅቱ ወይም በጊዜ ወደ መንግስት የጤና ድርጅት ሄደው ህክምና እንዲያደረጉ የሚያግዱትን ምክንያቶች በሰባት ጤና ድርጅቶች በታካሚዎ ምን እንደሚመስልና ህሙማን በወቅቱ ወይም በጊዜ ወደ መንግስት የጤና ድርጅት ሄደው ህክምና እንዲያደርጉ እንቅፋት ስለሚሆኑ ነገሮችን መረጃ ለማሳሰብ ነው።

#### **የፍቃደኝነት ማረጋገጫ**

ለጥናት ይረዳ ዘንድ አንዳንድ ጥያቄዎችን ልጠይቅዎት እፈልጋለሁ። ይህ ምናልባት----- ደቂቃዎችን ልወስድ ይችላል። የእርስዎ በዚህ ጥናት መሳተፍ በጣም ጠቀሜታ ስላለው ለሚቀርብልዎ ጥያቄ የሚያውቁትን በግልፅና በትክክል መልስ እንደሚሰጡ ተስፋ አለኝ። የሚሰጡኝ መልስና የህክምና ምርመራ ውጤትዎን በሚስጥር እንደሚያዝና ለጥናቱ አላማ ብቻ እንደምውል እንዲሁም ስሞ እዚህ መረጃ ላይ እንማይሰፍር አረጋግጥልዎታለሁ።

ተጨማሪ ለቡድን ውይይትና ለሌሎች ቃለመጠይቆች የሚነበብ

የሚሰጡኝ መረጃ በሙሉ በጣም ጠቃሚ ስለሆነ ምንክልባት ሁሉንም በማስታወሻዬ መያዝ ሊያዳግተኝ ስለሚችል መቅረፅ ድምፅ ልጠቀም አችልላለሁ።

ስለዚህ በዚህ መጠይቅ ለመሳተፍ ፍቃደኛ ነዎት ?

አዎ

አይደለም

አመሰግናለሁ

Universiitii Gondar fi Addis continentalii jidugaladula fayyaa Hawassa

Mana Barumsaa Xumuraa

Seensa

Maqaa kiyaa \_\_\_\_\_Hojjata/ Barataa\_\_\_\_\_.kayyon Qoranno kana,dhukubsatoota Juzaam Hospitallaa Bisdimoo tti kan galma'an Qama midha issani addan bafachuuf .

Waligaltee Gafif Debii Gad faggenya.

Mata dure kanaf kan ittianuu Dubisaa.

Qorranoo kiyyaf gafille tokkotokko sigafadha kan sa'atti tokko fudhatuu.

Hermannaa kee qo'anno kenyaaf gudoo barabarchisaa wanta'eef Gaffii kenyaaf debi'i dhugaa ta'ee akka nukanitaan kabajjan issin gafadha.

yadini kee fi debiin kee hundinuu dhoksaan wanqabamuuf fi maqaan kee hinbarrefamuu.hin caqafamuu. Yaddin kee gutumagututtii kayyoo Qo'annoo kanaff malee dhima kamiifu hin ollu.

Yaddin kee halaan barabchisa dha.anni hundahuu yaddanoo irratti qabachu hindada'uu ,kanafuu tepiin sagalee tee akkan warabadhuu naaf hayyamta. Atii mirgaa gutuu qabdaa yeroo fettee dhabuuf yoo sitti mija'uu bateejiduun illee.

Gaffii fi debi'ii godhuuf Naaf hayyamtaa?

Wali galeenjira\_\_\_\_\_

Lakki hinhayyamnee\_\_\_\_\_

Gudoo Galatoomii !





**Annex: 2 Checklist for recorded Review: for Assessment of disability status among leprosy patient**

Recorded in Bisidimo Hospital (2000-2002EFY)

Code NO \_\_\_\_\_

Unit LEPROSY no \_\_\_\_\_ card No \_\_\_\_\_

Questioner No \_\_\_\_\_

<b>Part I: Socio- demographic Characteristics</b>			
N0	Questions	Code	Remark
101	Age of the client	_____ Years	
102	Sex	1. Male                      2. Female	
103	Residence	1. Urban                      2. Rural	
104	How far does the patient live from Bisidimo Hospital ( KM)	_____ approximate KM Zone _____ Woreda _____	
105	Religion	1. Orthodox    2. Muslim    3. Protestant    99, other	
106	Marital Status	1, Never Married    2, Married    3, Divorced    4, other	
107	Educational Status	1. No education    2. Primary 3. Seconadry              4. Tertiary	
108	Occupations	1, Farmer    2, employeed              3, Merchant 4, Self employed    5, Daily labor    99, other	
<b>Part II: History the of patient during the first visit &amp; voluntary muscle testing</b>			
201	Method of case finding	1. Voluntary    2. Contact    3. Survey	
202	Main complaints	_____	
203	Category of leprosy	1, New    2, relapse    3, return after default    99, other	
204	Type of leprosy	1, MB                      2, PB	
205	Sensory loss in lesion	1. Present                      2. absent	
206	Number of skin lesion	1.    1 to 5                      2.    6 and more	
207	Leprosy nodules	1. present                      2. absent	
208	Skin smear done	1. Yes                      2. no	
209	If yes result	1. Posetive                      2. Negative	
210	Is there sign of nerve damage?	1. Yes                      2. No	
211	If yes duration in months	_____	
212	visual acuity counting fingers at 6m	1 Can count                      2, cannot count	

213	If cannot count	1. Right eye    2. Left eye    3. both	
214	Right eye closure	1. Strong    2.weak    3. paralyzed	
215	Left eye closure	1. Strong    2.weak    3. paralyzed	
216	Right thumb up	1. Strong    2.weak    3. paralyzed	
217	Left thumb up	1. Strong    2.weak    3. paralyzed	
218	Right fifth finger	1. Strong    2.weak    3. paralyzed	
219	Left fifth finger	1. Strong    2.weak    3. paralyzed	
220	Right foot up	1. Strong    2.weak    3. paralyzed	
221	Left foot up	1. Strong    2.weak    3. Paralyzed	
301	disability grade at diagnosis	1. G-0    2.G-1    3. G- 2	
302	Right Eye	1. G-0    2. G-2	
303	Left eye	1. G-0    2. G-2	
304	Right Hand	1, G-0    2.G-1    3. G-2	
305	Left Hand	1, G-.0    2.G-1    3. G- 2	
306	Right Foot	1, G-0    2,G-1    3, G- 2	
307	Left foot	1,G-0    2,G-1    3,G- 2	
308	If the patient started MDT	1.yes    2.no	
309	If yes regimen	1. MB- MD T    2. PM- MDT	
310	Steroid treatment started	1. Yes    2. no	
311	MDT treatment outcome	1. Completed    2. Defaulted    3. Death 4. Transferred out    5. Developed further disability	
312	Leprosy patient transform and referrals	1.Patient is referred to your health facility for registration and starting leprosy treatment  2. Transferred out to other facility to continue Rx  3. Patient is referred to other health facility for further investigation & management	
313	Care given for disabled patient While on MDT.	1. Yes    2. No  If yes _____	
314	Care given for disabilities after completion of leprosy treatment	1. Yes    2. no    3.unknown  If yes specify	

## **Semi structured Open ended questions Guide**

### **I. In-depth interview for leprosy patients grade 2 disability**

1. What is the first sign symptom of leprosy / disabled? (Explain how?)
2. How did you responded to your problem when you noticed signs of leprosy first and then after?
3. How is your understanding of leprosy (causes, Mode of transmission) of the disease?
4. How was your Initial reaction when diagnosed as Leprosy?
5. what is your Feeling in the early treatment of leprosy? (Explain how?)
6. What is your opinion on the causes of leprosy disability? (Explain how?)
7. How can you explain changes in your life when you are disabled?
8. What is the perception of your community?
9. What is the most feared part of leprosy and why?
10. How is (was) the treatment you have taken from the hospital?
11. How can explain participation of persons affected by Leprosy in Socialization?
12. What do you think are the reasons some people in your area develop leprosy and disability?
13. What is your opinion on the services provided in the leprosy and care for disabled?

## **Translated to Afan Oromo**

### **Semi structured Open ended questions Guide**

#### **I. Gafi fi debi'ii Gadfagenyaan dhukubsaatoota dhibee juzaamiif, dhiyatuu.**

1. Mallattoo Durra tan Dhibee juzaam maalii? Qamni midhamee hoo? Mee Ibssi
2. Akkammi tti lalatee yoo duraa dhukuba kana argitee fi ama bodaa hoo?
3. Akkam Hubanno kee wa'ee Dhukuba Juzaam ,Sababa issa ,akkata Itti dabruu?
4. Malltuu Sitti dhagayaamee yeroo durra dhibeen kun sitti argamee?
5. Maltuu sitti dhagayame yeroo walansaa duraa jalqabduu?
6. Yaddini kee akkam wa'ee qama midhama Juzaam?
7. Akkamitti Ibssitaa wa'ee Jijirama Qama midhaa keetti?
8. Hawassinni akkam tti lalaa Dhibee kana?/Juzaam
9. Dhibee Juzaam ka akkan sodatamuuf maliif?
10. Enyuu kan walansaa hoospitaala irra fudhatee?
11. Wa'ee hirmana hawassaa kessatti nama dhibee Juzaamiin midhamee ,enyuu tuu Ibsaa?
12. Maal yadaa wa'ee Namoota dhibee kanan Midhamani nannoo kannatti?
13. Yaddini kee maalii wa'ee tajajilaa dhibee Juzaamif kunuunsaa qama midhaamtootaf kenamuu?

## **II. In-depth interview for key informants health care providers**

1. How did you become a leprosy care provider?
2. How the community and the patients perceive (causes, mode of transmission, treatment) leprosy?
3. How do you see patient reaction during the diagnosis of leprosy (how Explain)
4. what do you think the reason patients give for delay in the leprosy treatment seeking ?
5. what is your perception and attitude toward Leprosy patients(are you comfortable working with Leprosy case, do you have personal concern as a risk working in this area (why explain
6. How do you feel the leprosy patients feeling toward public health facility services (health workers perception, waiting time)
7. How about the Knowledge and skill of health workers to diagnose and treat Leprosy?
8. What are the major problems in the management of Leprosy in your health facility ?(How Explain)
9. Do you think training and supervisions are important for leprosy service providers (why Explain )
10. How do you see the trend and the current magnitude of leprosy and grade 2 disability?(why Explain)
11. Who develop grade 2 disability (explain why)
12. How you prevent further disability among new cases?

## **Translated to Afan Oromo**

### **I. In-depth interview for key informants health care providers**

#### **Gafii fi Debi'ii gadfagoo Oggeyyi fayyaa dhimmi ilaluuf.**

1. Akkamittii kara Tajajila kuta walansa juzaam dhuuftee?
2. Hawassa fi Dhukubsaatootni akkam itti ilalan akkata dhibeen juzaam ittidarbruufi walansaa?
3. Akkam tti ibssita akkata dhukubsataan yeroo dura dhibee kanaan qoratamaan itti dhagayamuu? Mee Ibssi
4. Maal yadaa wa'ee dhukubsatoon osso hinqoratammin turuu issanni?
5. Assi dhikubsaatoota dhibee juzaam wallin hojjatuuf fedhii qabada YKN Rakoo qabaa jatee yadda Mee Ibssi?
6. Wa'ee Tajajila assitti kenamuu dhukubsataan akkamitti ilalaa jatee yadaa?
7. Hubannoo fi Bekuumssi akkasumass Muxxanoon Oggeyyi fayya ,Dhibee kana Qorachuuf yaluu irratti maal fakataa?
8. Rakkolleen gurgudoon dhibee Juzaam walanuurratti Jiraan maalffaa? Me Ibssi.
9. Leenjji fi Hoordofiin sagantaa kana Barbachisaa jataa? Me Ibssi.
10. Wa'ee dhibee Juzaam Halaa yeroo ama Midhaa haagam jatee yadda babalaachaa jira moo?Xiqacha jira
11. Enyuutuu Midha qama sadarka lamaaffaa qaba ? me Ibssi
12. Akkamitti Midha gudoo dhabamsiifta wara ama qabamanirra?

## ***Declaration***

*I, the undersigned declare that this thesis is my original work in partial fulfillment of the requirement for the degree of Master of Public Health. I also declare that it has never been presented in this or any other university and that all resources and materials used in the thesis have been duly acknowledged.*

*Student Name: Abiot Mitiku*

*Signature: \_\_\_\_\_*

*Place of submission: \_\_\_\_\_*

*Date of submission: \_\_\_\_\_*

*This thesis has been submitted with my approval as a university advisor.*

*Name: **Meaza Demissie (MD, MPH, PHD)***

*Signature: \_\_\_\_\_*

*Date of submission: \_\_\_\_\_*